

Organ donation in the ICU – a survey on next of kin response in two Swiss academic centres

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Summary

AIM OF THE STUDY: In the Swiss population, attitudes to organ donation are mostly positive. However, a high refusal rate by the next of kin may be observed. We aimed to investigate potential underlying reasons.

METHODS: In two independent Swiss tertiary care academic centres 167 next of kin were confronted with potential organ donation, over a period of 18 to 24 months. Of these, 147 could be contacted and were asked ≥ 6 months later to participate in a *post-hoc* survey (72-item questionnaire). Aspects related to conversations, time and care in the intensive care unit (ICU), underlying concepts for organ donation, impact on mourning, and other potential influencing factors were addressed.

RESULTS: The overall return rate was 66%. Seventy four of 77 (96%) next of kin stated that the request for organ donation was appropriate and they agreed to address the issue. Personal attitudes of next of kin regarding organ donation correlated with the decision for or against organ donation ($p < 0.0001$). Thirteen percent (8/62) reported that conversations with ICU physicians changed their decision. In 56% (18/32) of reports when organ donation was refused, the next of kin stated that presence of a documented will might have changed their decisions. Mourning was reported to be impaired by the request for organ donation in 8% (6/71), facilitated in 14% (10/71) and not affected in 77% (55/71) of cases. Twenty-seven percent (16/59) indicated that an opt-out policy for organ donation would subjectively have facilitated their decision and 81% (34/42) of consenting next of kin stated that an objection law should be put into place ($p < 0.0001$).

CONCLUSIONS: In this observational study, the majority of the next of kin stated that addressing organ donation did not affect mourning. Presence of a presumed will could likely facilitate grief and provide comfort for affected families. (Trial registration: ClinicalTrials.gov. Identifier: NCT 03612024. Date of registration: 24 July 2018.)

Introduction

Solid organ transplantation is an established therapy for end-stage organ failure [1, 2]. In Switzerland, federal law regulates organ and tissue transplantation, as well as organ donation via an opt-in system [3]. It is common sense that next of kin are always asked for consent to organ donation, even in the presence of a presumed positive patient will for organ donation. In clinical practice, an existing written or known presumed will of the patient is usually adhered to by the next of kin. In the case of a potential donor without written consent to organ donation and no next of kin available for consenting, organ donation is unlawful.

There is a growing mismatch between the limited number of donated organs and the increasing number of patients on transplantation waiting lists [4]. In Switzerland, the organ donation rate per million population (pmp) was 17.2 in 2017 [5]. Apart from Germany (9.7 pmp), all neighbouring countries have substantially higher rates: Austria 24.7 pmp, France 28.7 pmp, Italy 28.5 pmp [6]. Thus, a Swiss national action plan was implemented by the Federal Department of Health in 2014 to improve education/training, to establish national guidelines / checks, to clarify financial structures and to conduct public campaigns with the ultimate goal of increasing donation rates [7].

Refusal rates following a request for organ donation are high [4]. Interestingly, surveys on general attitudes towards organ donation in Switzerland reveal an acceptance rate of 92%, and 81% are willing to donate organs posthumously [8], whereas a consent rate of only about 30–40% is observed in many Swiss hospitals [9], including the participating institutions. As the underlying reasons are unclear, we collected answers and experiences from families confronted with organ donation after brain death (DBD) via a questionnaire-based investigation. Aspects related to conversations, time and care in the intensive care unit (ICU), underlying concepts (including the concept of brain death), impact on mourning, and other potential factors that might influence decision making were addressed.

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Methods

The questionnaire was developed in Bern and offered to the five Organ Donation Networks in Switzerland. Data were collected in the adult ICUs of two Swiss tertiary care academic centres (Department of Intensive Care Medicine, University Hospital of Bern and Department of Intensive Care Medicine, Lausanne University Hospital [CHUV]), with a catchment area of about 3–3.5 million inhabitants. At the time of the study, a donation after brain death (DBD) programme, but not donation after cardiac death (DCD), was established in Bern, whereas in Lausanne, both programmes were implemented. The 72-item questionnaire (German and French versions available) was designed in an exploratory manner by the team in Bern with the support of an external psychologist. The questionnaire addressed issues regarding conversations, time and care in the ICU, underlying concepts (including the concept of brain death), impact on mourning, and other potential factors relevant for decision-making (the questionnaires provided in the appendix in the PDF version of the manuscript).

All deaths in the ICU over a period of 18 months (Bern January 2016 to June 2017 and Lausanne July 2016 to December 2017) were screened for whether or not organ donation (DBD) was requested. In the event of a request, contact details of the primary contact person (next of kin) were recorded. At least 6 months after the death and following provision of written information, next of kin were contacted by telephone by an intensivist or by transplant coordinating staff, who requested permission to send the anonymous questionnaire. Subsequently the questionnaire was mailed in paper form to each family. If no contact by telephone was possible after several attempts (usually three times), the questionnaire was sent with an additional explanatory letter. No reminders were sent. No financial benefits applied. The need of approval by the local competent ethics committee of human research was waived in Bern (Nr. KEK-2017-00943). In accordance with the [recommendations of the ethics committee of Canton de Vaud](#), no approval was required in Lausanne.

Clinical routine during organ donation evaluation

The following clinical routine applied to potential organ donors in both institutions: according to guidelines and federal law, the family was first informed about the medical condition of the patient, including disclosure of the futile prognosis, or even brain death. In a second family meeting, the concept of brain death was explained as a prerequisite for organ donation. If the patient's will regarding organ donation was available in written form, the next of kin were informed. In situations where written consent existed but the next of kin disagreed with organ donation, no organ was donated, although federal law places the patient's will higher than that of next of kin. In these circumstances, organ donation is considered inadmissible and may complicate the next of kin grieving process.

If brain death had not yet occurred, the next of kin were informed that maintenance of ICU care would be established for a maximum of 48 hours. From the moment of brain death, another 12–20 hours are typically required for organ evaluation and allocation, and planning of solid organ retrieval.

Statistical analysis

For statistical analysis, GraphPad Prism 6, GraphPad Software, USA was used. Data are presented as numeric values (n) or means with percentages, as appropriate. Contingency tables were analysed using a chi-square test or Fisher's exact test. A two-tailed p-value of <0.05 was considered statistically significant.

Results

Overview and characteristics of next of kin

As shown ([figure 1](#)), a total of 167 interviews on organ donation were analysed. Twenty next of kin could not be contacted for technical reasons (invalid address / telephone number, or death). A total of 147 families were contacted. Twenty-five next of kin refused to participate and 122 questionnaires were sent. Eighty-one questionnaires were returned and analysed, corresponding to a retrieval rate of 66% ([fig. 1](#)). Detailed data are given ([table 1](#)). Sixty-three percent (22/35) of the next of kin consenting to organ donation returned the questionnaire, and 68% (59/87) of next of kin refusing organ donation did so. Responses were analysed according to availability (see appendix in the PDF version of the manuscript). Most participants were female (n = 44, 54%). The following relationships to the deceased person applied: husband/spouse n = 34 (42%), parent n = 23 (28%), sibling n = 12 (15%), daughter/son n = 11 (14%), not specified n = 1 (1%). The personal attitude towards organ donation was declared as: consenting 55 (68%), dismissive in 10 (12%) and undecided in 14 (17%); 2 gave no response (2%). Out of all questionnaires, 49 (60%) covered next of kin who consented to organ donation and 32 (40%) were from next of kin who refused organ donation. The presumed will of the deceased patient was known in 50 cases (62%), comprising 15 written documents (donor card, patient directive) and 41 volitions; multiple answers were possible to this question. In 72% of cases (n = 58), the final next of kin decision on organ donation corresponded to the presumed will, whereas in one single case the decision taken by the next of kin did not match the presumed patient will. In that case, the next of kin declared that the patient was not aware that waiting for brain death would prolong treatment on the ICU. In Lausanne, fewer next of kin rejecting organ donation participated in the survey (only French-speaking) compared with Bern (German- and French-speaking): Lausanne 18 consenting, 5 refusing; Bern 31 consenting, 27 refusing. All results of the questionnaire are provided in the appendix in the PDF version of the manuscript.

Organisational aspects and conversations on organ donation

Ninety percent of next of kin (72/80) reported that they were provided with sufficient time to be with their loved one during the ICU stay. Further, 94% (75/80) felt well cared for during the time in the ICU. Thirty-eight percent (30/78) claimed that, at least partly, the period of waiting to see the patient was too long. Additionally, 40% (32/80) indicated that the waiting period until they could talk to an ICU physician was at least partly too long. This perception appeared significantly more often in the group refusing organ donation (p = 0.0028). In 83% (66/80) the aspect

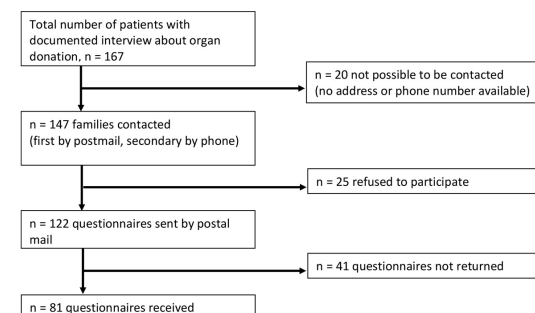
of potential organ donation was first addressed in the ICU, whereas in 11 cases (14%) the issue was first addressed either by the emergency department ($n = 5$) or by telephone ($n = 6$). In 41/79 (52%) of cases, potential organ donation was discussed in the first meeting with physicians. Forty-seven percent (35/74) of the organ donation requests occurred during off-hours, in the evening or during the night-time.

Ninety-six percent (74/77) of the next of kin reported that it was appropriate that organ donation was addressed. Ninety-nine percent (66/67) stated that they agreed with the physician's obligation to address the issue of organ donation. Sixteen of 59 (27%) indicated that an opt-out policy to organ donation would have facilitated their decision and 34/38 (89%) who consented to organ donation stated that an objection law should be put into place. This was statistically significantly different ($p < 0.0001$; Fisher's exact test) from the group not consenting to organ donation (in this group, eight responses [35%] were in favour of an opt-out policy).

Emotional aspects including mourning

In 10/79 cases (13%), the next of kin were still hoping for medical improvement at the time of the organ donation request. Twenty-eight of 77 (36%) stated their surprise that organ donation was asked for and in 13/77 cases (17%) they felt upset by this question. With regard to the concept of brain death, 71/78 (91%) agreed that explanations were necessary. Fifty-nine percent (44/75) were convinced that a person who is declared "brain dead" has in fact actually died / is dead.

Figure 1: Study flow chart illustrating the sequence of next of kin contact and questionnaire delivery.



Five of 71 (7%) reported that the request impaired their mourning process, whereas 10/71 (14%) felt that it facilitated mourning and 55/71 (77%) reported no effect on mourning. In one case the mourning process was considerably impaired by the organ donation request. Details on consenting vs non-consenting next of kin are given in [table 2](#). No significant differences were observed concerning mourning with regard to consenting and the knowledge of the presumed will of the deceased person ([table 3](#)).

Influence on consenting

Fifty-four of 62 next of kin (87%) reported that conversations with ICU physicians did not influence their decision regarding organ donation, whereas 8/62 (13%) indicated that it did change their decision. In cases of rejection of organ donation ($n = 32$), 4/32 responses (13%) signalled that having more time could have influenced their decision, and 6/32 (19%) stated that better explanation of the organ donation process might have changed their decision. In 18/32 cases (56%), the next of kin stated that an existing documented will of the deceased person might have changed the decision. Knowledge of the presumed will of the deceased patient and/or the language did not significantly affect consenting; however, personal attitudes regarding organ donation differed significantly between the groups with/without organ donation ([table 4](#)).

Discussion

The current study aimed to investigate in a detailed fashion next of kin decision making in regard to organ donation. In Bern, the refusal rate was higher than in Lausanne, with more interviews conducted in Berne (10.5% of deaths in Lausanne compared with 22.7% in Bern). In the light of potential differences in concepts of when to approach families, we rather focused on next of kin responses and not on potential centre-specific differences, which may be particular challenging to interpret. After analysing questionnaire-based responses from two independent academic centres in a descriptive fashion, we observed that the vast majority of the next of kin reported that being asked for organ donation was acceptable and did not affect mourning. They judged that the presence of a presumed will facilitated grief and provided help for families confronted with

Table 1: Characteristics and numbers of the interviews with next of kin regarding consent/refusal of organ donation.

| | | Lausanne | Bern | Total |
|---------------------------|----------------|----------|------|-------|
| Numbers of deaths in ICU | | 506 | 503 | 1009 |
| Consent to organ donation | All interviews | 53 | 114 | 167 |
| | Yes | 27 | 32 | 59 |
| | No | 26 | 82 | 108 |
| Missing contact data | Total | 6 | 14 | 20 |
| | Yes | 0 | 3 | 3 |
| | No | 6 | 11 | 17 |
| Refuse to participate | Total | 12 | 13 | 25 |
| | Yes | 4 | 3 | 7 |
| | No | 8 | 10 | 18 |
| Questionnaire mailed | Total | 35 | 87 | 122 |
| | Yes | 24 | 26 | 50 |
| | No | 11 | 61 | 72 |
| Returned questionnaire | Total | 22 | 59 | 81 |

a decision as to whether to donate. Furthermore, we identified potential intra-hospital organisational aspects that might affect the final decision.

Previous investigations have pointed to the fact that “in-hospital reasons” may be at least partly responsible for increased refusal rates [10–13]. We found that prolonged waiting time, i.e., time from first contact of the next of kin to meeting a physician, appeared as a potential factor that might affect refusal rates. In general, time until a treating

physician was available for consultation consistently appeared in the survey as an important and potentially related factor. Thus, it appeared that the underlying communication concept of organ donation may be important, and this could also be reflected by the fact that in some cases, next of kin decisions changed during the process of considering organ donation. Although the exact underlying reasons remain unclear due to the observational nature of this investigation, we demonstrated that the final decision to donate may not be static for some next of kin. The scientific con-

Table 2: Comparison of the groups consenting / refusing organ donation (according to available data, no answer in italics).

| | Consent yes n = 49 | Consent no n = 32 | p-value |
|---|-----------------------|----------------------|---------|
| The question regarding organ donation did upset me | | | |
| – Yes | 4 / 8% | 9 / 32% | 0.0109* |
| – No | 45 / 92% | 19 / 68% | |
| – No answer | 0 | 4 | |
| Do you believe that a person who has been declared braindead is really dead? | | | |
| – Fully applies | 30 / 68% | 14 / 45% | 0.1327† |
| – Partly applies | 12 / 27% | 14 / 45% | |
| – Does not apply | 2 / 5% | 3 / 10% | |
| – No answer | 5 | 1 | |
| The request for organ donation affected my mourning process: the process was... | | | |
| ...considerably impaired | 0 / 0% | 1 / 4% | 0.1507† |
| ...impaired | 3 / 7% | 2 / 7% | |
| ...not impaired | 32 / 73% | 23 / 85% | |
| ...facilitated | 9 / 20% | 1 / 4% | |
| – No answer | 5 | 5 | |

Available data (percentages) are given. * Fisher's exact test; † chi-square test

Table 3: Effect of consent, personal attitude towards organ donation and presumed will (if available) on the mourning process (71 answers, no answer = 10).

| | Mourning process impaired | Mourning process facilitated | Mourning process not impaired | p-value |
|---|---------------------------|------------------------------|-------------------------------|---------|
| Consent to / rejection of organ donation process: (no answer = 0) | | | | |
| – Consent | 3 / 50% | 9 / 90% | 32 / 58% | 0.133* |
| – Rejection | 3 / 50% | 1 / 10% | 23 / 42% | |
| Personal attitude towards organ donation: (no answer = 2) | | | | |
| – I would donate | 2 / 50% | 10 / 100% | 38 / 84% | 0.003* |
| – I wouldn't donate | 1 / 25% | 0 / 0% | 7 / 16% | |
| – I don't know | 1 / 25% | 0 / 0% | 0 / 0% | |
| The presumed will of the deceased person was... (no answer = 0) | | | | |
| ...known | 4 / 67% | 8 / 80% | 33 / 60% | 0.475* |
| ...not known | 2 / 33% | 2 / 20% | 22 / 40% | |

Data available (percentages) are given. * Chi-square test.

Table 4: Language, personal attitude, knowledge of presumed will of the next of kin, and correspondence of the final decision with the presumed will.

| | Consent yes n = 49 | Consent no n = 32 | p-value |
|---|-----------------------|----------------------|----------|
| German speaking | 21 / 47% | 24 / 53% | 0.006* |
| French speaking | 28 / 78% | 8 / 22% | |
| Personal attitude towards organ donation: | | | |
| – I would donate | 44 / 92% | 11 / 35% | <0.0001† |
| – I wouldn't donate | 0 / 0% | 10 / 32% | |
| – I don't know | 4 / 8% | 10 / 32% | |
| – No answer | 1 | 1 | |
| The presumed will of the patient was... | | | |
| ...known | 32 / 64% | 18 / 36% | 0.4858* |
| ...unknown | 17 / 55% | 14 / 45% | |
| Did the final decision correspond to the presumed will: | | | |
| – Yes | 37 / 79% | 21 / 68% | 0.3198† |
| – No | 0 / 0% | 1 / 3% | |
| – Not known | 10 / 21% | 9 / 29% | |
| – No answer | 2 | 1 | |

Data available (percentages) are given. * Fisher's exact test; † chi-square test.

cept of brain death and potential organ donation may be viewed as important to next of kin confronted with the request for organ donation [14–16].

We observed that the existence of a presumed will may have facilitated decision making, and that this could influence the mourning process and might provide comfort to the next of kin. A considerable number stated that the decision whether to donate might have been different if a known presumed will had existed (56%, $n = 18$, of all those rejecting organ donation in the interview). Thus, it appeared that presence of a presumed will may lead to both increased organ donation rates and family relief. As the presented data are – to the best of our knowledge – the only currently available data for Switzerland, we speculate that an opt-out policy on organ donation would affect donation rates [17, 18].

Our study has important limitations that deserve discussion. First, the retrieval rate of the (not formally validated) questionnaire was 66%, which might impose a bias on our findings. Also, the group consenting to organ donation taking part in the survey was larger than the group refusing organ donation. Second, the study was performed in two academic centres and had an observational design, with all the inherent limitations driven by study design. Centre-specific differences in procedures and the proportions of participants might impact on our results. However, the questionnaire might be adopted by additional centres, enabling future multicentre comparisons. Also, excluding next of kin confronted with donation after cardiac death might be problematic, as the proportion of such donors in Switzerland increased in recent years and comparison with donation after brain death may be difficult. Third, and importantly, we deliberately designed the analysis in an anonymised fashion to provide participants with the highest level of data protection. However, this prevented us from drawing conclusions on exact patient-related factors, such as age, ethnicity or underlying pathologies leading to brain death. This was considered out of the scope of the current analysis and might be pursued in subsequent studies.

Conclusions

In this observational study including the primary next of kin of deceased individuals who qualified for potential organ donation, the majority stated that addressing the question of organ donation did not impact the mourning process. Furthermore, we identified potential intra-hospital organisational aspects such as waiting time that might affect the final decision. Finally, the next of kin judged that existence of a presumed will would have facilitated grief and might have provided help for families confronted with a request for organ donation.

Availability of data and materials

All data generated or analysed during this study are included in this published article and its supplementary information files in the appendix in the PDF version of the manuscript.

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Disclosure statement

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Appendix: Supplementary information

Supplementary file 1: Table providing all responses to the questionnaire.

Supplementary file 2: Questionnaire in English.

Supplementary file 3: Questionnaire in German.

Supplementary file 4: Questionnaire in French.

| All responses to the questionnaire. | | | | | | | | | | | | |
|-------------------------------------|---|---|----------------------|---|----------------------|--|----------------------|--|----------------------|---|----------------------|-----------|
| | Question | Response | Number(s) of answers | Response | Number(s) of answers | Response | Number(s) of answers | Response | Number(s) of answers | Response | Number(s) of answers | Response |
| 1 | care provided by intensive care unit (ICU): general impression | | | | | | | | | | | |
| 1.1. | Did the nursing staff introduce themselves? | <input type="checkbox"/> yes | 77 | <input type="checkbox"/> no | 2 | no answer | 2 | | | | | |
| 1.2. | Did the medical staff introduce themselves? | <input type="checkbox"/> yes | 79 | <input type="checkbox"/> no | 0 | no answer | 2 | | | | | |
| 1.3. | The ICU staff was made a competent impression. | <input type="checkbox"/> fully applies | 76 | <input type="checkbox"/> partly applies | 2 | <input type="checkbox"/> does not apply | 0 | no answer | 3 | | | |
| 1.4. | I had enough time to ask questions. | <input type="checkbox"/> fully applies | 72 | <input type="checkbox"/> partly applies | 7 | <input type="checkbox"/> does not apply | 1 | no answer | 1 | | | |
| 1.5. | The ICU staff made a compassionate impression. | <input type="checkbox"/> fully applies | 68 | <input type="checkbox"/> partly applies | 9 | <input type="checkbox"/> does not apply | 1 | no answer | 3 | | | |
| 1.6. | Me and my family felt well cared for at the ICU. | <input type="checkbox"/> fully applies | 75 | <input type="checkbox"/> partly applies | 4 | <input type="checkbox"/> does not apply | 1 | no answer | 1 | | | |
| 1.7. | The information provided by the ICU doctors was | <input type="checkbox"/> comprehensible | 70 | <input type="checkbox"/> partly comprehensible | 10 | <input type="checkbox"/> incomprehensible | 1 | | | | | |
| 1.8. | My next of kin received the best possible care before he/she died. | <input type="checkbox"/> fully applies | 73 | <input type="checkbox"/> partly applies | 2 | <input type="checkbox"/> does not apply | 0 | no answer | 6 | | | |
| 1.9. | I've had to wait too long until I've could visit the patient. | <input type="checkbox"/> fully applies | 10 | <input type="checkbox"/> partly applies | 20 | <input type="checkbox"/> does not apply | 48 | no answer | 3 | | | |
| 1.10. | I've had to wait too long until I've could talk to an ICU doctor. | <input type="checkbox"/> fully applies | 12 | <input type="checkbox"/> partly applies | 20 | <input type="checkbox"/> does not apply | 48 | no answer | 1 | | | |
| 1.11. | During the stay at the ICU I had enough time to be with my next of kin. | <input type="checkbox"/> fully applies | 75 | <input type="checkbox"/> partly applies | 4 | <input type="checkbox"/> does not apply | 1 | no answer | 1 | | | |
| 1.12. | The premises during the conversations were adequate. | <input type="checkbox"/> fully applies | 70 | <input type="checkbox"/> partly applies | 7 | <input type="checkbox"/> does not apply | 1 | no answer | 3 | | | |
| 1.13. | At what time of day was the first conversation regarding possible organ donation held? | <input type="checkbox"/> in the morning | 15 | <input type="checkbox"/> in the afternoon | 24 | <input type="checkbox"/> in the evening | 22 | <input type="checkbox"/> at night | 13 | no answer | 7 | |
| 2 | conversation s: regarding organ donation | | | | | | | | | | | |
| 2.1 | Where was organ donation first addressed? | <input type="checkbox"/> at the emergency unit | 6 | <input type="checkbox"/> on the telephone | 5 | <input type="checkbox"/> at the ICU | 66 | <input type="checkbox"/> at another hospital | 0 | <input type="checkbox"/> others | 3 | no answer |
| 2.2 | Who first addressed organ donation? | <input type="checkbox"/> I've | 8 | <input type="checkbox"/> doctor | 65 | <input type="checkbox"/> nursing staff | 3 | no answer | 5 | | | 1 |
| 2.3 | Organ donation was discussed already in the first meeting with the ICU doctors. | <input type="checkbox"/> yes | 41 | <input type="checkbox"/> no | 38 | no answer | 2 | | | | | |
| 2.4 | Was the question regarding organ donation surprising? | <input type="checkbox"/> yes | 28 | <input type="checkbox"/> no | 49 | no answer | 4 | | | | | |
| 2.5 | Did this question upset you? | <input type="checkbox"/> yes | 13 | <input type="checkbox"/> no | 64 | no answer | 4 | | | | | |
| 2.6 | Did you find it appropriate that organ donation was addressed? | <input type="checkbox"/> yes | 74 | <input type="checkbox"/> no | 3 | no answer | 4 | | | | | |
| 2.7 | Conversations about organ donation were (multiple answers possible) | <input type="checkbox"/> too short | 0 | <input type="checkbox"/> too long | 1 | <input type="checkbox"/> adequate in length | 74 | <input type="checkbox"/> comprehensible | 70 | <input type="checkbox"/> incomprehensible | 3 | no answer |
| 2.8 | Once the question about organ donation had been raised, were you aware that the situation was medically hopeless? | <input type="checkbox"/> yes | 76 | <input type="checkbox"/> no | 2 | no answer | 3 | | | | | 2 |
| 2.9 | Were you still hoping for a medical improvement when organ donation was discussed? | <input type="checkbox"/> yes | 10 | <input type="checkbox"/> no | 69 | no answer | 2 | | | | | |
| 2.10 | During the conversation about organ donation, were there any issues that bothered you (e.g. too many people, language, other reasons)? | <input type="checkbox"/> yes | 9 | <input type="checkbox"/> no | 70 | no answer | 2 | | | | | |
| 2.12 | My personal attitude towards organ donation is: | <input type="checkbox"/> I would want to donate | 55 | <input type="checkbox"/> I do not want to donate | 10 | <input type="checkbox"/> undecided | 14 | no answer | 2 | | | |
| 2.13 | My own next of kin know my wishes regarding organ donation. | <input type="checkbox"/> yes | 65 | <input type="checkbox"/> no | 13 | no answer | 3 | | | | | |
| 2.14 | I have expressed my wishes in written form. | <input type="checkbox"/> yes | 35 | <input type="checkbox"/> no | 42 | no answer | 4 | | | | | |
| 3 | the term brain death: | | | | | | | | | | | |
| 3.1 | The term 'brain death' was familiar to me before the disease of my next of kin. | <input type="checkbox"/> yes | 58 | <input type="checkbox"/> no | 22 | no answer | 1 | | | | | |
| 3.2 | The term 'brain death' was explained to me/us. | <input type="checkbox"/> yes | 73 | <input type="checkbox"/> no | 8 | | | | | | | |
| 3.3 | I understood the concept of 'brain death' after the conversation. | <input type="checkbox"/> fully applies | 57 | <input type="checkbox"/> partly applies | 14 | <input type="checkbox"/> does not apply | 9 | no answer | 1 | | | |
| 3.4 | I was able to memorize the concept of brain death. | <input type="checkbox"/> fully applies | 46 | <input type="checkbox"/> partly applies | 25 | <input type="checkbox"/> does not apply | 3 | no answer | 5 | | | |
| 3.5 | Did you find the explanations regarding brain death necessary? | <input type="checkbox"/> fully applies | 71 | <input type="checkbox"/> partly applies | 7 | <input type="checkbox"/> does not apply | 0 | no answer | 3 | | | |
| 3.6 | Do you believe that a person who has been declared braindead is really dead? | <input type="checkbox"/> fully applies | 44 | <input type="checkbox"/> partly applies | 26 | <input type="checkbox"/> does not apply | 5 | no answer | 6 | | | |
| 3.7 | After the explanations on brain death, I was better able to understand the fact that my next of kin was dead despite 'normal' physical appearance | <input type="checkbox"/> yes | 67 | <input type="checkbox"/> no | 7 | no answer | 7 | | | | | |
| 4 | decision on organ donation | | | | | | | | | | | |
| 4.1 | Has an organ donation been agreed to? | <input type="checkbox"/> yes | 49 | <input type="checkbox"/> no | 32 | | | | | | | |
| 4.2 | The wishes of my next of kin regarding organ donation were known. | <input type="checkbox"/> yes | 50 | <input type="checkbox"/> no | 31 | | | | | | | |
| 4.3 | (provided that known): The wishes were | <input type="checkbox"/> discussed by word of mouth | 41 | <input type="checkbox"/> Donor card | 9 | <input type="checkbox"/> Advance directive | 5 | <input type="checkbox"/> written | 10 | | | |
| 4.4 | The final decision taken correspond to the presumed will of the next of kin. | <input type="checkbox"/> yes | 58 | <input type="checkbox"/> no | 1 | unknown | 19 | no answer | 3 | | | |
| 5 | in case the wishes of the deceased were not followed | | | | | | | | | | | |
| 5.2 | In case an organ donation was rejected, which of the following could have had an influence on the decision? | <input type="checkbox"/> more time | 4 | <input type="checkbox"/> better explanation of the process | 6 | <input type="checkbox"/> a documented will of my next of kin | 18 | | | | | |
| 5.4 | Within the family - was there any unanimity regarding the suspected wishes? | <input type="checkbox"/> yes | 61 | <input type="checkbox"/> no | 7 | no answer | 13 | | | | | |
| 5.5 | Within the family, were there different views on what the presumed wishes were? | <input type="checkbox"/> yes | 8 | <input type="checkbox"/> no | 57 | no answer | 16 | | | | | |
| 5.6 | Would you/the family still come to the same decision today? | <input type="checkbox"/> yes | 65 | <input type="checkbox"/> no | 4 | no answer | 12 | | | | | |
| 5.8 | Do you agree with physicians' legal obligation to address the issue of organ donation? | <input type="checkbox"/> yes | 66 | <input type="checkbox"/> no | 1 | no answer | 14 | | | | | |
| 5.9 | Should everyone become an organ donor, provided they have not objected to organ donation during their lifetime (so-called objection law)? | <input type="checkbox"/> yes | 42 | <input type="checkbox"/> no | 19 | no answer | 20 | | | | | |
| 5.10 | Would an existing objection law (or opting-out system) have facilitated the decision? | <input type="checkbox"/> yes | 16 | <input type="checkbox"/> no | 43 | no answer | 22 | | | | | |
| 5.11 | Did the conversation change the decision regarding organ donation? | <input type="checkbox"/> yes | 8 | <input type="checkbox"/> no | 54 | no answer | 19 | | | | | |
| 5.12 | I felt pressurised during the conversation. | <input type="checkbox"/> yes | 5 | <input type="checkbox"/> no | 58 | no answer | 18 | | | | | |
| 6 | recommendations follow-up | | | | | | | | | | | |
| 6.3 | I would like to receive aftercare as a next of kin. | <input type="checkbox"/> yes | 13 | <input type="checkbox"/> no | 56 | no answer | 12 | | | | | |
| 6.4 | If "yes": | <input type="checkbox"/> involving a personal meeting | 10 | <input type="checkbox"/> involving meeting other affected next of kin | 4 | <input type="checkbox"/> other | 1 | | | | | |
| 6.5 | The request for organ donation affected my mourning process: the process was | <input type="checkbox"/> considerably impaired | 1 | <input type="checkbox"/> impaired | 5 | <input type="checkbox"/> not impaired | 55 | <input type="checkbox"/> facilitated | 10 | no answer | 10 | |
| 7 | questions regarding transplant coordination in case of organ donation approval | | | | | | | | | | | |
| 7.1 | I remember the transplant coordinator. | <input type="checkbox"/> yes | 35 | <input type="checkbox"/> no | 18 | no answer | 28 | | | | | |
| 7.2 | The assistance provided by the transplant coordination service was | | | | | | | | | | | |
| 7.3 | ... professional | <input type="checkbox"/> fully applies | 40 | <input type="checkbox"/> partly applies | 1 | <input type="checkbox"/> does not apply | 0 | no answer | 40 | | | |
| 7.4 | ... has met my needs | <input type="checkbox"/> fully applies | 33 | <input type="checkbox"/> partly applies | 6 | <input type="checkbox"/> does not apply | 0 | no answer | 42 | | | |
| 7.5 | ... compassionate | <input type="checkbox"/> fully applies | 31 | <input type="checkbox"/> partly applies | 1 | <input type="checkbox"/> does not apply | 4 | no answer | 45 | | | |
| 7.6 | ... an additional burden | <input type="checkbox"/> fully applies | 1 | <input type="checkbox"/> partly applies | 6 | <input type="checkbox"/> does not apply | 30 | no answer | 44 | | | |
| 7.7 | I felt under pressure when I had to decide which organs/tissues to donate. | <input type="checkbox"/> yes | 4 | <input type="checkbox"/> no | 45 | no answer | 32 | | | | | |
| 7.8 | Did the process of organ donation correspond to what transplant coordination services had explained? | <input type="checkbox"/> yes | 43 | <input type="checkbox"/> no | 3 | no answer | 35 | | | | | |
| 7.9 | Were there any deviations (e.g. timing, information flow)? | <input type="checkbox"/> yes | 3 | <input type="checkbox"/> no | 38 | no answer | 40 | | | | | |
| 7.10 | Are you aware that a donor's next of kin can always contact transplant coordination services | | | | | | | | | | | |
| 7.9 | ... regarding information about the recipient(s) (in an anonymised fashion)? | <input type="checkbox"/> yes | 33 | <input type="checkbox"/> no | 15 | no answer | 33 | | | | | |
| 7.10 | ... in case anything is still unclear during the organ donation process? | <input type="checkbox"/> yes | 27 | <input type="checkbox"/> no | 19 | no answer | 35 | | | | | |
| 7.11 | Transplant coordination services defaults to calling next of kin one year later. Such a phone call | <input type="checkbox"/> is appreciated | 24 | <input type="checkbox"/> is fine with me | 17 | <input type="checkbox"/> is not necessary | 4 | <input type="checkbox"/> is disturbing | 2 | no answer | 34 | |
| 8 | personal information | | | | | | | | | | | |
| 8.1 | I am the deceased's: | <input type="checkbox"/> spouse | 34 | <input type="checkbox"/> parent | 23 | <input type="checkbox"/> son/daughter | 11 | <input type="checkbox"/> sibling | 12 | no answer | 1 | |

1. care provided by intensive care unit ☐C☐D general impression

- ☐ **personal information**
 8.1 I am the deceased's: ☐ spouse ☐ parent ☐ son/daughter ☐
 8.2 I am: ☐ female ☐ male
 8.3 Further comments you would like to let us know:

Fragebogen für Angehörige

1. Betreuung durch Intensivstation: genereller Eindruck

- 1.1. Hat sich das Pflegepersonal der Intensivstation vorgestellt? ☐ Ja ☐ Nein
- 1.2. Hat sich das ärztliche Personal der Intensivstation vorgestellt? ☐ Ja ☐ Nein
- 1.3. Das Personal der Intensivstation empfand ich als kompetent. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
- 1.4. Ich hatte genügend Zeit meine Fragen zu stellen. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
- 1.5. Das Personal der Intensivstation nahm emotional Anteil. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
- 1.6. Ich und meine Angehörigen fühlten sich auf der Intensivstation gut betreut. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
- 1.7. Die Informationen durch die Ärzte der Intensivstation waren ☐ verständlich ☐ teilweise verständlich ☐ unverständlich
- 1.8. Mein Angehöriger wurde optimal betreut, bevor er/sie starb. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
- 1.9. Es kam vor, dass ich/wir zu lange warten mussten, bis ich/wir ans Bett konnte/n. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
- 1.10. Es kam vor, dass ich/wir zu lange warten mussten, bis wir mit dem Arzt der Intensivstation ein Gespräch führen konnten. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
- 1.11. Ich hatte auf der Intensivstation genügend Zeit, um bei meiner/m Angehörigen zu sein. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
- 1.12. Die Räumlichkeiten während den Gesprächen waren angemessen. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
- 1.13. Zu welcher Tageszeit fand das erste Gespräch hinsichtlich einer möglichen Organspende statt? ☐ morgens ☐ mittags ☐ abends ☐ nachts

2. Gespräch in denen nach Organspende gefragt wurde

- 2.1. Wo wurde das Thema Organspende erstmals angesprochen? ☐ Notfallstation ☐ telefonisch ☐ Intensivstation ☐ anderes Spital ☐
- 2.2. Das Thema Organspende wurde erstmals durch wen angesprochen? ☐ durch uns Angehörige ☐ Arzt ☐ Pflege ☐
- 2.3. Das Thema Organspende wurde bereits im ersten Gespräch mit den Ärzten thematisiert. ☐ Ja ☐ Nein
- 2.4. War die Frage nach Organspende überraschend? ☐ Ja ☐ Nein
- 2.5. Haben Sie diese Frage als schlimm empfunden? ☐ Ja ☐ Nein
- 2.6. Finden Sie es angemessen, dass man die Frage nach Organspende stellt? ☐ Ja ☐ Nein
- 2.7. Ich empfand die Gespräche zur Organspende (mehrere Angaben möglich) ☐ zu kurz ☐ zu lang ☐ lang genug ☐ verständlich ☐ kompliziert
- 2.8. War Ihnen zum Zeitpunkt der Frage nach Organspende bewusst, dass medizinisch die Situation für Ihre/n Angehörige/n aussichtslos war und keine weitere Hilfe möglich war? ☐ Ja ☐ Nein
- 2.9. Hatten Sie noch Hoffnung auf eine medizinische Besserung als die Organspende besprochen wurde? ☐ Ja ☐ Nein
- 2.10. Als über die Organspende gesprochen wurde, gab es etwas, was sie gestört hat (z. Bsp. zu viele Personen, Sprache, ...)? ☐ Ja ☐ Nein
- 2.11. Falls ja (Freitextfeld):
- 2.12. Meine persönliche Einstellung zur Organspende ist: ☐ Ich würde spenden wollen. ☐ Ich würde nicht spenden wollen. ☐ Ich weiss es nicht.
- 2.13. Meine Angehörigen kennen meinen Willen. ☐ Ja ☐ Nein
- 2.14. Ich habe meinen Willen schriftlich festgelegt. ☐ Ja ☐ Nein

3. Zum Begriff Hirntod

- 3.1. Der Hirntod war mir bereits vor der Erkrankung meines Angehörigen bekannt. ☐ Ja ☐ Nein
- 3.2. Der Hirntod wurde erklärt. ☐ Ja ☐ Nein
- 3.3. Den Hirntod habe ich nach dem Gespräch verstanden. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
- 3.4. Ich konnte mir das Konzept des Hirntodes merken. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
- 3.5. Fanden Sie die Erklärungen bezüglich Hirntod notwendig? ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
- 3.6. Glauben Sie, dass man dann wirklich tot ist? ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
- 3.7. Durch die Erklärungen zum Hirntod verstand ich die Situation, dass mein Angehöriger trotz normalem Aussehen tot ist, besser. ☐ Ja ☐ Nein

4. Entscheidung Organspende

- 4.1. Wurde einer Organspende zugestimmt? ☐ Ja ☐ Nein
- 4.2. Der Wille meines Angehörigen war bekannt. ☐ Ja ☐ Nein
- 4.3. Sofern bekannt: Der Wille war ☐ mündlich besprochen ☐ schriftlich dokumentiert (☐ Spenderausweis ☐ Patientenverfügung ☐)
- 4.4. Entsprach der getroffene Entscheid dem mutmasslichen Willen des Angehörigen? ☐ Ja ☐ Nein ☐ nicht bekannt
- 4.5. Warum war der Verstorbene für oder gegen die Organspende? (Freitext, z. Bsp. Unversehrtheit des Körpers, Wunsch anderen Menschen zu helfen, ...)

Falls nicht dem Wunsch des Verstorbenen entsprochen wurde

- 5.1. Was hat dazu geführt, dass anders entschieden wurde? (Freitext)
- 5.2. Falls eine Organspende abgelehnt wurde, was hätte die Entscheidung allenfalls beeinflusst?
☐ mehr Zeit ☐ bessere Erklärung des Ablaufs ☐ der dokumentierte Wille meines Angehörigen
- 5.3. Anderes (Freitext):
- 5.4. Innerhalb der Familie gab es Einstimmigkeit bezüglich mutmasslichem Willen. ☐ Ja ☐ Nein
- 5.5. Innerhalb der Familie gab es verschiedene Auffassungen über den mutmasslichen Willen. ☐ Ja ☐ Nein
- 5.6. Würden Sie heute den gleichen Entscheid fällen? ☐ Ja ☐ Nein
- 5.7. Falls nein, warum? (Freitext)
- 5.8. Sind sie mit der gesetzlichen Verpflichtung des Arztes einverstanden, dass er/sie das Thema Organspende ansprechen muss? ☐ Ja ☐ Nein
- 5.9. Sollten alle Organspender/in werden, sofern sich die Person zeitlebens nicht dagegen ausgesprochen hat (sogenannte Widerspruchslösung / vermutete Zustimmung)? Ein Angehörigengespräch würde auch in diesem Fall stattfinden. ☐ Ja ☐ Nein
- 5.10. Hätte eine bestehende Widerspruchslösung in Ihrem Fall den Entscheid erleichtert? ☐ Ja ☐ Nein
- 5.11. Hat das Gespräch den Entscheid bezüglich Organspende geändert? ☐ Ja ☐ Nein
- 5.12. Ich fühlte mich während des Gesprächs unter Druck. ☐ Ja ☐ Nein
- 5.13. Falls ja, inwiefern: (Freitext)

Empfehlungen Nachbetreuung

- 6.1. Was könnte / sollte man anders (bzw. besser) machen? (Freitext)
- 6.2. Während der Betreuung auf der Intensivstation hat mir folgender Aspekt gefehlt: (Freitext)
- 6.3. Eine Nachbetreuung der Angehörigen würde ich in Anspruch nehmen. ☐ Ja ☐ Nein
- 6.4. Falls ja: ☐ in Form von persönlicher Betreuung ☐ Treffen mit anderen Angehörigen in ähnlicher Situation ☐ anderes
- 6.5. Durch die Anfrage zur Organspende wurde mein Trauerprozess ☐ nachhaltig beeinträchtigt ☐ beeinträchtigt ☐ nicht beeinträchtigt ☐ erleichtert

Fragen zur Transplantationskoordination im Falle einer Zustimmung zur Organspende

- 7.1. Ich kann mich an die Transplantationskoordinatorin erinnern. ☐ Ja ☐ Nein
- Die Betreuung durch die Transplantationskoordination war
- 7.2. ... professionell ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
- 7.3. ... hat meinen Bedürfnissen entsprochen ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
- 7.4. ... empathisch ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
- 7.5. ... eine zusätzliche Belastung ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
- 7.6. Ich fühlte mich unter Druck bei der Entscheidungsfindung, welche Organe/Gewebe gespendet werden dürfen. ☐ Ja ☐ Nein
- 7.7. Entsprach der Ablauf der Organspende dem, wie es die Transplantationskoordination erklärt hatte? ☐ Ja ☐ Nein
- 7.8. Gab es Abweichungen (z. Bsp. zeitlicher Ablauf, Informationsfluss)? ☐ Ja ☐ Nein
- Ist Ihnen bekannt, dass sich die Familie des Spenders/ der Spenderin jederzeit bei der Transplantationskoordination melden kann
- 7.9. ... für Auskünfte zu den Empfänger*ern (anonymisiert)? ☐ Ja ☐ Nein
- 7.10. ... falls etwas beim Organspendeprozess nicht optimal gelaufen ist? ☐ Ja ☐ Nein
- 7.11. Nach einem Jahr werden die Angehörigen telefonisch von der Transplantationskoordination kontaktiert, dieser Anruf ☐ wird geschätzt ☐ geht in Ordnung ☐ braucht es nicht ☐ ist eine störende Belastung
- 7.12. Freitext zur Betreuung durch die Transplantationskoordination:

Eigene Angaben

- 8.1. Das eigene Verhältnis zur verstorbenen Person: ☐ (Ehe)Partner/in ☐ Mutter/Vater ☐ Sohn/Tochter ☐
- 8.2. Das eigene Geschlecht: ☐ weiblich ☐ männlich
- 8.3. Weitere Bemerkungen, die im Formular nicht erwähnt sind, können Sie hier - oder falls mehr Platzbedarf bestehen auf der Rückseite - ergänzen:

Questionnaire L'intention proches

1. Prise en charge au soins intensifs: impression générale

- 1.1. Le personnel soignant s'est-il présenté? ☐ Oui ☐ Non
- 1.2. Les médecins se sont-ils présentés? ☐ Oui ☐ Non
- 1.3. J'ai jugé le personnel des soins intensifs compétent. ☐ tout ☐ fait ☐ en partie ☐ pas du tout
- 1.4. J'ai eu suffisamment de temps pour poser mes questions. ☐ tout ☐ fait ☐ en partie ☐ pas du tout
- 1.5. Le personnel des soins intensifs a pris en compte mes émotions. ☐ tout ☐ fait ☐ en partie ☐ pas du tout
- 1.6. Mes proches et moi nous sommes sentis bien pris en charge. ☐ tout ☐ fait ☐ en partie ☐ pas du tout
- 1.7. Les informations données par les médecins étaient ☐ compréhensibles ☐ en partie ☐ incompréhensibles
- 1.8. Mon proche a bénéficié d'une prise en charge optimale avant son décès. ☐ tout ☐ fait ☐ en partie ☐ pas du tout
- 1.9. Il est arrivé d'attendre trop longtemps avant de voir mon/notre proche. ☐ tout ☐ fait ☐ en partie ☐ pas du tout
- 1.10. Il est arrivé d'attendre trop longtemps avant de pouvoir parler avec le médecin des soins intensifs. ☐ tout ☐ fait ☐ en partie ☐ pas du tout
- 1.11. J'ai eu suffisamment de temps pour être auprès de mon proche dans le service des soins intensifs. ☐ tout ☐ fait ☐ en partie ☐ pas du tout
- 1.12. Les locaux utilisés pour les entretiens étaient adaptés. ☐ tout ☐ fait ☐ en partie ☐ pas du tout
- 1.13. A quel moment eut lieu le premier entretien abordant un possible don d'organes? ☐ matin ☐ midi ☐ soir ☐ nuit

2. Entretien durant lequel la question du don d'organes a été abordée

- 2.1. Le sujet du don d'organes a-t-il été abordé pour la première fois? ☐ Urgences ☐ au téléphone ☐ aux soins intensifs ☐ dans un autre hôpital ☐ Personnel soignant
- 2.2. Qui a thématiqué le don d'organes en premier? ☐ nous (proches) ☐ Médecin
- 2.3. Le sujet du don d'organes a-t-il été abordé avec les médecins lors du premier entretien d'aj? ☐ Oui ☐ Non
- 2.4. La question concernant un éventuel don d'organes était-elle inattendue? ☐ Oui ☐ Non
- 2.5. Cette question a-t-elle été perçue comme douloureuse? ☐ Oui ☐ Non
- 2.6. Trouvez-vous adéquat de poser la question concernant un don d'organes? ☐ Oui ☐ Non
- 2.7. J'ai vécu l'entretien sur le don d'organes (plusieurs réponses possibles) ☐ trop court ☐ trop long ☐ assez long ☐ compréhensible ☐ compliqué
- 2.8. Au moment de la question concernant le don d'organes, était-il clair pour vous que la situation de votre proche était, d'un point de vue médical, sans espoir? ☐ Oui ☐ Non
- 2.9. Aviez-vous encore de l'espoir d'une amélioration de la situation lors de l'entretien sur le don d'organes? ☐ Oui ☐ Non
- 2.10. Avez-vous été d'accord par quelque chose lors de l'entretien (par ex. trop de personnes présentes, langue, ...)? ☐ Oui ☐ Non
- 2.11. Si oui (texte libre):
- 2.12. Ma position personnelle quant au don d'organes est: ☐ Je serais d'accord de donner mes organes. ☐ Je ne serais pas d'accord. ☐ Je ne sais pas.
- 2.13. Mes proches connaissent mes volontés. ☐ Oui ☐ Non
- 2.14. J'ai consigné mes volontés par écrit. ☐ Oui ☐ Non

3. Le concept de la mort cérébrale

- 3.1. Je connaissais l'expression mort cérébrale avant d'y être confronté. ☐ Oui ☐ Non
- 3.2. L'expression mort cérébrale nous a été expliquée. ☐ Oui ☐ Non
- 3.3. J'ai compris l'expression mort cérébrale suite à l'entretien. ☐ tout ☐ fait ☐ en partie ☐ pas du tout
- 3.4. J'ai pu retenir le concept de la mort cérébrale. ☐ tout ☐ fait ☐ en partie ☐ pas du tout
- 3.5. Selon vous, les explications concernant la mort cérébrale sont-elles nécessaires? ☐ tout ☐ fait ☐ en partie ☐ pas du tout
- 3.6. Croyez-vous alors que les gens sont réellement déçus? ☐ tout ☐ fait ☐ en partie ☐ pas du tout
- 3.7. À travers les explications de la mort cérébrale, j'ai compris que mon proche était mort, malgré son apparence normale. ☐ Oui ☐ Non

4. Décision concernant le don d'organe

- 4.1. Un don d'organes a-t-il été approuvé? ☐ Oui ☐ Non
- 4.2. La volonté de mon proche était connue. ☐ Oui ☐ Non
- 4.3. Si connue: La volonté avait été discutée ensemble ☐ consignée par écrit (carte de donneur) ☐ directives anticipées ☐ inconnu
- 4.4. La décision finale correspond-elle à la volonté présumée du patient? ☐ Oui ☐ Non
- 4.5. Pourquoi le défunt était-il pour ou contre le don d'organes? (Texte libre, p.ex : intégrité du corps, souhait d'aider quelqu'un d'autre, ...):

5. Dans le cas où la volonté de la personne décédée n'était pas connue

- 5.1. Qu'est-ce qui vous a aidé à prendre une décision? (texte libre)
- 5.2. Dans le cas où le don d'organes a été refusé, qu'est-ce qui aurait pu influencer votre décision? ☐ Plus de temps ☐ Plus d'explications quant au processus ☐ Avoir la volonté écrite de mon proche
- 5.3. Autre (Texte libre):
- 5.4. La famille était-elle unanime concernant la volonté présumée de votre proche? ☐ Oui ☐ Non
- 5.5. Y avait-il des divergences dans la famille quant à la volonté présumée? ☐ Oui ☐ Non
- 5.6. Prendriez-vous aujourd'hui la même décision? ☐ Oui ☐ Non
- 5.7. Si non, pourquoi? (Texte libre)
- 5.8. Êtes-vous d'accord avec l'obligation légale du médecin d'aborder le sujet du don d'organes? ☐ Oui ☐ Non
- 5.9. Est-ce que tout un chacun devrait être considéré comme donneur d'organes, à moins qu'il ne s'y soit opposé de son vivant – connu comme le régime du consentement présumé? Tout en incluant également une discussion avec les proches. ☐ Oui ☐ Non
- 5.10. Est-ce que le régime du consentement présumé aurait facilité votre décision? ☐ Oui ☐ Non
- 5.11. Avez-vous changé d'avis suite à l'entretien portant sur le don d'organes? ☐ Oui ☐ Non
- 5.12. Je me suis senti(e) sous pression durant l'entretien. ☐ Oui ☐ Non
- 5.13. Si oui, dans quelle mesure? (Texte libre)

6. Recommandations à le suivi

- 6.1. Que devrions-nous améliorer? (Texte libre)
- 6.2. Lors de la prise en charge aux soins intensifs, certains aspects ont-ils manqué? (Texte libre)
- 6.3. J'aurais souhaité bénéficier d'un accompagnement. ☐ Oui ☐ Non
- 6.4. Si oui: ☐ Sous la forme d'un entretien personnel ☐ Rencontre avec d'autres proches ayant vécu une situation similaire ☐ autre
- 6.5. Suite à la question du don d'organes, mon processus de deuil a été ☐ durablement altéré ☐ altéré ☐ n'a pas été influencé ☐ facilité

7. Questions relatives à la coordination de transplantation en cas de consentement au don d'organes

- 7.1. Je me rappelle de la coordinatrice de transplantation. ☐ Oui ☐ Non
- La prise en charge par la coordinatrice de transplantation était
- 7.2. ... professionnelle ☐ tout ☐ fait ☐ en partie ☐ pas du tout
- 7.3. ... à répondre à mes besoins ☐ tout ☐ fait ☐ en partie ☐ pas du tout
- 7.4. ... empathique ☐ tout ☐ fait ☐ en partie ☐ pas du tout
- 7.5. ... une charge supplémentaire ☐ tout ☐ fait ☐ en partie ☐ pas du tout
- 7.6. Je me suis senti(e) sous pression lorsqu'il a fallu décider quels organes allaient être donnés. ☐ Oui ☐ Non
- 7.7. Le processus de don d'organes a-t-il été expliqué en détail par la coordinatrice de transplantation? ☐ Oui ☐ Non
- 7.8. Ya-t-il eu des différences (p.ex. timing, flux d'information)? ☐ Oui ☐ Non
- Saviez-vous que la famille du donneur/euse pouvait en tout temps contacter la coordination de transplantation
- 7.9. ... pour avoir des informations quant aux receveurs (anonymement)? ☐ Oui ☐ Non
- 7.10. ... dans le cas où quelque chose ne s'est pas déroulé de la manière optimale dans le processus du don d'organes? ☐ Oui ☐ Non
- 7.11. Après un an, les proches sont contactés par téléphone par la coordination de transplantation, cet appel ☐ est apprécié ☐ est ok ☐ n'est pas nécessaire ☐ est une gêne supplémentaire
- 7.12. Texte libre pour la prise en charge par la coordination de transplantation:

8. Données personnelles

- 8.1. Lien de parenté avec la personne décédée: ☐ Epoux-se/partenaire ☐ Mère/Père ☐ Fils/Fille ☐
- 8.2. Genre: ☐ Femme ☐ Homme
- 8.3. Des commentaires supplémentaires peuvent être ajoutés ci-après ou au verso: